Continuing Education Module

### Umbilical Cord Blood: Information for Childbirth Educators

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#### **ABSTRACT**

Umbilical cord blood was once thought of as a waste product. Now, years after the first successful umbilical cord blood transplant, more families seek information about whether or not to save their newborn's cord blood. Childbirth educators may be one of the main sources that an expectant family depends on to gain more knowledge about cord blood banking in order to make an informed decision. Preserving umbilical cord blood in public banks is advisable for any family; however, it is recommended that expectant families only consider private cord blood banking when they have a relative with a known disorder that is treatable by stem cell transplants. The childbirth educator is encouraged to be well versed on the topic of cord blood banking, so that as questions from class participants arise, the topic can be explored and addressed appropriately.

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At the end of a recent childbirth class, I found two couples engaged in a lengthy discussion. In the course of the conversation, both couples agreed that their goal was to do the best things for their pregnancy and birth. They were attending childbirth classes to learn how to support normal birth. They each were planning to attend breastfeeding classes. As their conversation continued, the first couple described their decision to bank the umbilical cord blood of their yet unborn daughter. They were adamant that their decision was the best action for them because they had a strong family history of myasthenia gravis. They stated that they had researched the issue by talking to several different cord blood banks, and they had decided on one particular bank because it processed the cord blood without the use of the anticoagulant

drug, heparin. The couple went on to parrot back the information that the cord blood bank had told them. It was evident that the first couple wanted what was best for their yet unborn child.

The second couple listened intently to the conversation, interjecting that they hadn't considered cord blood banking, and they looked toward me. They started asking the other couple, and me, many questions about cord blood banking. What is the cost? How is it done? What are the uses of cord blood? Is it only used to treat the baby later in life? Will cord blood treat myasthenia gravis? And finally, is it worth the time, effort, and money to invest in cord blood banking?

I had some information about the very basics of umbilical cord blood banking, but I did not have the

answers to most of the second couple's questions. The first couple had some of the answers, but based on the limited knowledge I had, I felt that the information that the first couple shared was simply the information that the cord blood bank had supplied. I suspected that the cord blood bank had only shared information that was in its best interest to gain another customer. Therefore, my suspicions put me on a path to learn more about umbilical cord blood and, thus, cord blood banking and cord blood transplants.

One of the first things I learned is that the couples in my childbirth class were not unique. In fact, research indicates that most pregnant women are underinformed about the issue of cord blood banking (Fox et al., 2007). While reviewing the literature on cord blood banking, I also found that the information available for nurses and childbirth educators often comes from private cord blood banks or their employees (Cord Blood Registry, 2009; Wolf, 1998, 1999), thus introducing the chance of bias.

#### STEM CELL TRANSPLANTS

To begin a discussion of umbilical cord blood banking, it must first be understood that the component from the blood that is salvaged is the stem cells. Stem cells are unspecialized cells that are the basis of all tissue and organ cells of the body. There are three main sources of stem cells in humans: embryonic stem cells, adult stem cells, and umbilical cord stem cells. Embryonic stem cells are generally used in research but not in clinical practice. Adult stem cells are found in various locations in the human body, but they are most commonly found in bone marrow (McGuckin & Forraz, 2008). Over the years, transplants of bone marrow stem cells have been used clinically to treat disease processes in which stem cells are beneficial. Umbilical cord blood stem cells were historically considered a waste product of the birthing process but are now known to have up to 10 times more stem cells than adult bone marrow (Gunning, 2007).

Research on stem cell transplants began in the 1950s, with successful bone marrow transplants occurring in the 1970s, often to treat cancer patients whose own bone marrow was destroyed by chemotherapy and radiation. The first successful umbilical cord blood stem cell transplant was reported as occurring in the late 1980s. The recipient was a 6-year-old American boy from North Carolina who was treated for Fanconi's anemia (a genetic disorder) at Hospital St. Louis in Paris, France, using cord blood obtained from his younger sister's birth. Interestingly, more than 20 years after the transplant,

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this young man is alive and well. Not only did he survive long term, but both his immune system and his blood were transformed by the transplant of his sister's cord blood stem cells. Soon after this first documented cord blood stem cell transplant, the first public umbilical cord blood bank was established in 1991 in New York (McGuckin & Forraz, 2008).

Prior to transplanting any type of tissue, a "matching" process must occur to increase the success of the transplant and decrease the likelihood that the transplant will be rejected. The rejection of a transplanted tissue is called "graft versus host disease." The matching process dates back to the late 1950s when the human leukocyte antigens were discovered. There are two classes of human leukocyte antigens. The first class is located on the surface of almost all of the cells with a nucleus within the body of the cell. The second class of human leukocyte antigens is located on the surface of immune cells. Each of the two classes of antigens has three subgroups, creating six antigens for which matching can occur. Thus, a "6 of 6" matching of the antigens represents a "perfect" match. Beyond the matching process, other factors contribute to the success or failure of a stem cell transplant. These factors include, but are not limited to, the age of both the donor and the patient, the type of disease being treated, and the number of stem cells being transplanted (Moise, 2005).

#### USES OF STEM CELL TRANSPLANTS

Four main types of physical conditions are treated with stem cell transplants: cancers, blood disorders, congenital metabolic disorders, and immunodeficiencies (see Table 1). Examples of cancers that are treated with stem cells are both lymphoma and leukemia. Nonmalignant hemologic disorders also account for a fair share of the recipients of stem cells. Examples of these blood disorders are various types of anemias, such as sickle-cell anemia and Fanconi's anemia (the first disorder treated with umbilical cord blood stem cells). Stem cells have also been used to treat various metabolic disorders, such as adrenoleukodystrophy. The fourth major category of uses for stem cells is in treating immunodeficiencies, such as Duncan's disease or adenosine deaminase deficiency (Drew, 2005; Moise, 2005).

TABLE 1
Examples of Conditions Treated With Stem Cell Transplants\*

Cancers	Congenital Metabolic		
	Blood Disorders	Disorders	Immunodeficiencies
Acute lymphocytic leukemia	Sickle-cell anemia	<ul> <li>Adrenoleukodystrophy</li> </ul>	<ul> <li>Adenosine deaminase deficiency</li> </ul>
<ul> <li>Acute myelogenous leukemia</li> <li>Chronic myelogenous leukemia</li> <li>Myelodysplastic syndrome</li> <li>Neuroblastoma</li> <li>Hodgkin's disease</li> <li>Non-Hodgkin's lymphoma</li> <li>Burkitt's lymphoma</li> </ul>	<ul> <li>Fanconi's anemia</li> <li>Thalassemia</li> <li>Evan's syndrome</li> <li>Congenital cytopenia</li> <li>Aplastic anemia</li> <li>Diamond–Blackfan anemia</li> <li>Amegakaryocytic thrombocytopenia</li> </ul>	<ul> <li>Gunther's disease</li> <li>Gaucher's disease</li> <li>Hurler's syndrome</li> <li>Hunter's syndrome</li> <li>Krabbe's disease</li> <li>Sanfilippo's syndrome</li> <li>Tay-Sachs' disease</li> </ul>	<ul> <li>Wiskott-Aldrich's syndrome</li> <li>Duncan's disease</li> <li>Ataxia-telangiectasia</li> <li>DiGeorge's syndrome</li> <li>Myelokathexis</li> <li>Hypogammaglobulinemia</li> <li>Severe combined immunodeficiency</li> </ul>

Note. \*Adapted from Drew (2005) and Moise (2005).

Researchers continue to investigate new applications of stem cells. Ballen (2006) reported on studies examining the use of stem cells for treating autoimmune diseases, such as lupus, systemic sclerosis, and multiple sclerosis. Gunning (2007) reported on stem cell research for regenerative uses for heart attacks, stroke, spinal cord injury, diabetes, liver injury, and even traumatic brain injury. However, Gunning also noted that these regenerative uses for stem cells are purely in the research stage and, so far, no tangible evidence supports any clinical uses beyond the diseases that are currently being treated.

## ADVANTAGES OF UMBILICAL CORD BLOOD STEM CELLS

There are several advantages of using umbilical cord blood stem cells over bone marrow stem cells for transplants (see Table 2). The first advantage is that umbilical cord blood is relatively easy to collect and process. Once considered a substance to be thrown away after a birth, now the cord blood can be easily saved. After it is saved and sent to a storage facility, the cord blood is quickly available for use within days to weeks after processing. In contrast, bone marrow stem cells can take much longer to find a match, collect the sample, and process. The process for bone marrow transplantation can take from weeks to months. The collection process for cord blood is not painful to either mother or child and can be

Regenerative uses for stem cells are purely in the research stage and, so far, no tangible evidence supports any clinical uses beyond the diseases that are currently being treated. done either prior to or after the delivery of the placenta (Gonzalez-Ryan, VanSyckle, Coyne, & Glover, 2000; Percer, 2009). Bone marrow transplants, on the other hand, require the donor to be hospitalized, anesthetized, and experience postcollection pain and discomfort. Thus, compared to cord blood, bone marrow collection and transplantation of stem cells are more costly (Drew, 2005; Moise, 2005).

Another advantage of using umbilical cord blood stem cells is the decreased risk of the transmission of infectious disease. This particular advantage is partly because umbilical cord blood is almost never contaminated by Epstein-Barr virus or cytomegalovirus (Drew, 2005; Gonzalez-Ryan et al., 2000). Additionally, the processing of cord blood includes collecting data on the history of infection during the mother's pregnancy. For example, if the pregnant woman has a history of group B streptococcus, active genital herpes, or prolonged rupture of membranes and chorioamnionitis, umbilical cord blood is not saved. Generally, samples of the mother's blood are also drawn to test for infectious diseases, such as hepatitis, human immunodeficiency virus, and syphilis (Moise, 2005). Furthermore, after the cord blood units are collected, they are screened for

# TABLE 2 Advantages of Umbilical Cord Blood Stem Cells Versus Bone Marrow Stem Cells

- Ease of collection
- · No risk for mother or child
- Less time needed for processing (more quickly available for use)
- · Less costly than bone marrow collection
- Less risk for transmission of infection
- · Less need for stringent antigen typing
- Less rejection

disease, and any units that are deemed contaminated or infected are thrown away (Gunning, 2007).

The stem cells obtained from umbilical cord blood are also less likely than bone marrow stem cells to be rejected in transplants. Considered to be immunologically immature, umbilical cord blood stem cells produce significantly fewer natural killer cells, creating a substantial decrease in rejection. Consequently, cord blood stem cells require less rigorous antigen tissue matching for transplants than bone marrow stem cells (Sullivan, 2008). Research indicates that a mismatch of up to two antigen sites still provides successful clinical outcomes (Ballen, 2006; Fox et al., 2007). In fact, researchers report that the rate of rejection for cord blood stem cell transplants is half the rate of rejection for bone marrow transplants (Ballen et al., 2001). When compared directly in cases of mismatched antigens, there was clearly less rejection in transplants involving cord blood stem cells than bone marrow stem cells (Moise, 2005).

# DISADVANTAGES OF UMBILICAL CORD BLOOD STEM CELLS

Despite the benefits of using umbilical cord blood stem cells for transplant, the process also has some disadvantages (see Table 3). For stem cell transplants to be successful, measurable signs of engraftment must occur. Engraftment is the opposite of rejection and indicates that the stem cell transplant is "working." Two measurable signs of engraftment are the recovery of both neutrophil (a type of white blood cell) and platelet (a clotting factor) production. These two clinical signs of recovery take longer to occur in umbilical cord blood stem cell transplants than in bone marrow stem cell transplants. In other words, the lab values for white blood cell production and platelet production take longer to increase after umbilical cord blood stem cell transplants than after bone marrow stem cell transplants (Hess, 1997; Moise, 2005).

One of the factors that influence engraftment time is cell dose (Gunning, 2007). Cell dose is directly related to the volume of umbilical cord blood collected. Cell dose refers to the amount of useful stem cells in the sample of blood. Because of the limited volume of cells collected from cord blood, the amount of stem cells in cord blood is approximately 10% less than the amount obtained from bone marrow (Moise, 2005). A single unit of umbilical cord blood usually contains 50 to 200 ml of blood (Gonzalez-Ryan et al., 2000). If an amount of cord blood is less than this minimum volume, the unit is discarded as being unsatisfactory because the

TABLE 3

Disadvantages of Umbilical Cord Blood Stem Cells

- · Slow engraftment
- · Limited cell dose
  - Small volume of unit
  - Additional cell doses unavailable
- Autologous donation may have limited benefit owing to hereditary disorders
- Storage issues
  - Unknown length of long-term storage
  - Cost related to long-term storage
  - Quality control

cell dose of the sample would not be high enough. Collecting an insufficient volume of cord blood occurs in about 50% or more cases of cord blood collection (Drew, 2005). In general, fewer stem cells are needed for cord blood transplantation, and usually a volume of 50 to 100 ml of cord blood will provide enough of a cell dose for a child or small adult. However, should the recipient need additional stem cells, it is impossible to obtain more stem cells from the infant because the cord blood volume is a limited amount (Percer, 2009).

Another important disadvantage that is not well understood by the general public is the limited use of an infant's own umbilical cord blood stem cells later in life, called an autologous transplant. Commercial cord blood banks often advertise the banking of the infant's cord blood as "biologic insurance." However, the chance that a child would be able to use his or her own cord blood is extremely small: from a 1:400 to a 1:200,000 chance over the child's lifetime (Sullivan, 2008). In fact, there are certain instances in which the use of one's own umbilical cord blood is contraindicated, as in cases when the defect is of a genetic origin. For example, autologous cord blood stem cells cannot be used to treat malignant cancers such as leukemia because the genetic mutations for the cancer already exist on the DNA of the cord blood. Using one's own stem cells would be, in effect, "contaminating" oneself with the same disease process (Percer, 2009).

Another important consideration for autologous use is that, currently, it is unknown how long umbilical cord blood will maintain its usefulness while frozen. Research indicates that cord blood stem cells

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can be maintained up to 15 years, but it is unknown if the cells would be preserved over the entire lifetime of a person (Ballen et al., 2001; Hess, 1997). Furthermore, financial costs are associated with maintaining the cord blood over time. Kaimal, Smith, Laros, Caughey, and Cheng (2009) studied the cost-effectiveness of private umbilical cord blood banking for autologous use and concluded that it was not cost-effective in most instances because the chances that it would be used are extremely small.

Finally, there is a significant lack of regulation for umbilical cord blood banking. The lack of quality control, in turn, affects the quality of the specimen available for transplant. Some cord blood banks have submitted to voluntary accreditation, but the process of accreditation varies from bank to bank, whether public or private (McGuckin & Forraz, 2008; Moise, 2005).

#### TYPES OF UMBILICAL CORD BLOOD BANKS

There are three types of umbilical cord blood banks: private, public, and direct-donation banks. The private bank is a commercial, for-profit entity that often advertises directly to expectant parents. These banks are designed for the sole use of the families who have saved the cord blood. Private banks charge an initial fee for collection and processing and, then, a yearly fee to maintain the specimen. Another fee is often charged when a sample is removed for testing or treatment (Moise, 2005).

Public umbilical cord blood banks accept altruistic donations of cord blood and do not charge donation fees. Donated units are also processed, antigen typed, and frozen, ready for use. Unlike private banks, public banks do not reserve the units for the family that donated them; rather, units are available to the general public. In fact, a family that donates the blood would be no more likely to be a recipient of the blood than anyone else in the general population. Public cord blood banks function much like venous blood banks. The blood is released on an "as-needed" basis, and a processing fee may be charged to recoup some of the cost of storage (Moise, 2005; Percer, 2009).

Direct-donation umbilical cord blood banks function as an amalgamation of public and private banks. Direct-donation banks collect cord blood without charging fees. In addition, they accept autogenous donations and reserve them only for the family, especially for a family whose infant has a sibling with a disorder that may be treated with umbilical cord blood stem cells (Moise, 2005).

#### PROFESSIONAL ORGANIZATIONS' POSITIONS

The American College of Obstetricians and Gynecologists (ACOG, 2008) recommends giving pregnant women information about umbilical cord blood banking that is free from bias. According to ACOG, the chance of a child or family member needing a stem cell transplant is about 1 in 2,700. Therefore, ACOG recommends the collection and banking of cord blood only when an immediate family member has a known diagnosis for which stem cells are currently being used for treatment, and not for potential future uses.

The American Academy of Pediatrics (AAP, 2007) states that the use of banked umbilical cord blood as "biologic insurance" is unwarranted. The AAP also notes that many of the claims of private cord blood banks are unfounded. Unlike ACOG, the AAP recommends cord blood collection and banking for all families; however, their distinction is that all cord blood should be banked in public banks for use by the general population. In one study, the researchers reported that when pediatric transplant specialists were surveyed, overall, they did not recommend private cord blood banking (Thornley et al., 2009). The AAP recommends private cord blood banking *only* if a full sibling has a medical diagnosis for which stem cells are currently being used for treatment.

Lamaze International (2010) does not have a policy specific to umbilical cord blood banking; however, the organization has a specific policy that prohibits advertising of private cord blood banks in any Lamaze media vehicle. This policy was most recently updated and revised in July 2010. In addition, in their book, The Official Lamaze Guide: Giving Birth With Confidence, Lothian and DeVries (2010) reinforce the AAP's position that expectant families are vulnerable to the marketing strategies of private cord blood banks. The authors go on to say that expectant parents should know that banking umbilical cord blood does not guarantee a cure. Likewise, there is no guarantee that a private umbilical cord blood bank will be able to adequately preserve the cord blood until a time when it is needed. One potential reason for being unable to preserve the cord blood is that the private cord blood bank could go out of business.

#### ETHICAL CONCERNS

Some ethical concerns over umbilical cord blood banking warrant mention. As previously stated, the AAP(2007)acknowledgesthatclaimsinadvertisements for private cord blood banks are not accurate. In fact, some of the statements made by private cord blood banks are outright misleading (Fox et al., 2007), which raises questions about how informed consent for cord blood collection is obtained. Legally, the cord blood belongs to the child, but the consent of the mother alone is usually obtained for collection, and the consent of the father is rarely considered (Ballen, 2006). Because the cord blood now has a "value," the person who obtains consent and that same person's professional connection to the private cord blood bank may come into question (Pinch, 2001).

Additional ethical concerns about umbilical cord blood banking involve the timing of clamping the umbilical cord after birth. Overall, the issue of when to clamp and cut the umbilical cord is controversial. There is no consensus on how early or how late in the birthing process the umbilical cord ought to be clamped and cut, although the cord obviously still provides nourishment and removes waste until it is clamped or spontaneously stops pulsing (Lothian & DeVries, 2010). However, some practitioners might clamp the umbilical cord early in an effort to maximize the amount of cord blood obtained for banking, and thus "short change" the child and allow the infant to become anemic (Drew, 2005).

#### **CONCLUSION**

Umbilical cord blood was once thought of as a waste product of the birthing experience, but now it is valued for its content of stem cells. Today, more than 20 years after the first successful umbilical cord blood stem cell transplant, more families are seeking information about whether or not to invest in saving their newborn's umbilical cord blood. Saving the cord blood in public banks is a worthy undertaking for any family. It is recommended that expectant families only consider cord blood banking in private banks when they have a relative with a known disorder that is already treatable by stem cell transplants. Moreover, expectant families should not rely on commercial cord blood banks as their sole source of information about cord blood banking.

Let's look back at the expectant couple in my childbirth class who asked about banking their infant's umbilical cord blood. They should not base their decision to bank the umbilical cord blood on the type of anticoagulant used to preserve the sample; likewise, they should not obtain all of their information on cord blood banking from the private cord blood bank, whose major agenda is to gain another client. Instead, they must be encouraged to research various resources for reliable information

#### TABLE 4

Online Resources for Information About Umbilical Cord Blood Banking

#### Parent's Guide to Cord Blood Foundation Web site

http://parentsguidecordblood.org/

American College of Nurse–Midwives—"Cord Blood Banking—What It's All About" (from 2008 *Journal of Midwifery & Women's Health*, 53[2], 161–162)

• http://www.midwife.org/siteFiles/news/sharewithwomen53\_2.pdf

### American Academy of Pediatrics—"Frequently Asked Questions About Cord Blood Banking"

• http://www.aap.org/advocacy/releases/jan07cordbloodfaq.htm

### National Marrow Donor Program—"Cord Blood Donation: Frequently Asked Questions"

 http://www.marrow.org/HELP/Donate\_Cord\_Blood\_Share\_Life/ Cord\_Blood\_Donation\_FAQs/index.html

(see Table 4). If they have evidence that stem cells are used currently to treat a specific disease process that is affecting a family member, and is not simply a proposed idea, then it might be in their best interest to privately bank the umbilical cord blood. However, they should be aware that simply banking the cord blood does not ensure a cure, and they would most likely be banking the blood not for the current baby, but for some other family member. They must also be aware of the cost involved in the banking process. Finally, if they do not have a relative with a disease process treated with stem cells or there is no evidence that stem cells are used to treat the diseases that are known to be in their family, then they should consider public banking of the umbilical cord blood (if they have access to a public cord blood bank).

Childbirth educators may be one of the first resources that an expectant family turns to in order to gain more knowledge to make an informed decision about collecting umbilical cord blood in the birthing process. Therefore, the childbirth educator should be well versed on the topic, so that as questions from class participants arise, the multiple facets of umbilical cord blood banking can be explored.

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